SPINAL CORD

Vol. 4 No. 2

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Folic Acid Dietary Recommendation

The U.S. Public Health Service has recommended that all women of childbearing age consume 0.4 milligrams (mg) daily of folic acid to reduce the risk of neural tube defects (NTD). Each year in the United States 2500 infants are born with NTDs, and 16 are born in Arkansas with spina bifida, one of several types of NTDs.

NTDs occur around the 27th day of pregnancy, often before a woman realizes she is pregnant. For unknown reasons the neural tube fails to develop properly. However, these defects can be reduced by the proper use of folic acid, a Bcomplex vitamin.

Folic acid is found in several foods such as orange juice, dried beans, cereals, bread, rolls, and crackers. Green vegetables, like okra, broccoli, spinach, and asparagus are good sources, as is liver. Folic acid is also available in many multivitamin capsules. Even with all of these sources, the average American gets only about half of the protective amount of folic acid in their diet.

To protect against NTDs, women should begin taking folic acid several weeks prior to conception. The Arkansas Spina Bifida Association recommends that all women who have one child with a NTD, such as spina bifida, take 0.4 mg of folic acid a day, the equivalent of one multivitamin. All women who are thinking about becoming pregnant should be under the care of a physician. If you have any questions about folic acid, talk to your physician or call the Arkansas Genetics Program at 1-800-358-7299.

Innovative Housing Approach Yields Big Results

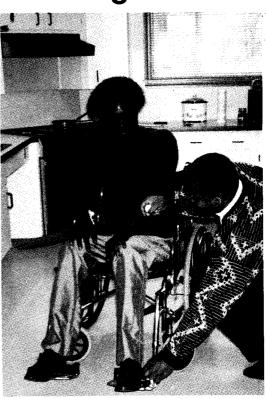
An innovative approach to affordable and accessible housing is exactly what the Pine Bluff Housing Authority/HUD had in mind when they came up with the concept of a demonstration project which involved design modification and retrofitting of an existing house to accommodate a family whose membership includes a disabled person. Most important in the renovation design criteria were accessibility solutions integrated into the household environment and not simply "add on" amenities to meet the needs of people with special living requirements.

Such a house was a dream come true for Nathaniel Green and family. Nathaniel Green is a 32 year old who was involved in an automobile crash in 1986 and experienced paraplegia. According to Nathaniel, his mother and father had made application to be placed on the housing authority waiting

list some years ago and knew nothing of this new concept. Pine Bluff Housing Authority (PBHA) spokesman Bill Freeman reported the family was the first on their waiting list meeting the particular needs criteria.

Green's home is accessed from the outside by a covered ramp leading from the carport to a three foot, well-lit side entrance door. Inside, improved open spaces, passageways and placement of specially selected appliances and fixtures enhance easy movement and access to normal household activities for persons with physical impairments. Location of electrical and telephone service outlets have been made more accessible to those in a seated position. Easier access and utilization by

See Housing, page 4



Case Manager Bobby Johnson adjusts Nathaniel Green's wheelchair in the kitchen of Green's new home.

SPINAL COURIER

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Cheryl L. Vines Executive Director

Thomas L. Farley Editor

The Arkansas State Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

BUCKLE UP!

Arkansas Spinal Cord Injury Association

Are you bored, looking for an opportunity to meet with other people interested in spinal cord injury and want to have an impact on disability issues in Arkansas? Then the Arkansas Spinal Cord Injury Association is looking for you!

The Association works to better our state for people with spinal cord disabilities in the areas of accessibility, public awareness, education and services. Membership is open (fees are \$18 per year, but scholarships for memberships are available), so call the association at 225-3546 today and join! The Association is also looking for a new corresponding secretary: if you are interested in this volunteer position, call President Stacy Willis at the number above.

Big Demand for New Book!

Just a note that the ASCC Resource and Education Center has been swamped with requests to borrow Enabling Romance. A Guide to Love. Sex and Relationships for the Disabled. Please be patient!

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Support Group Commentary

Dear Editor:

My first thought on being asked to come to a support group was, "I DON'T WANT TO GO."

To hang around a bunch of gimps was the last thing I would choose to do. Whinny, sick people in wheelchairs, why I wouldn't be unique or special, I'd have to share the spotlight, I wouldn't get near the attention I'm used to,

Worst of all, they would be like me, and I already knew me too well.

I could not have been more wrong! Some of them were GIRLS!

We're not all alike, not even close, all of us arrived by a different path, and carried different baggage. In a very short time we became us. Friends, that I'm sure will never be out of touch with each other, no matter how the winds of change blow. To be able to ask somebody what you can't ask anybody else, because they don't have any idea what you're talking about and cannot understand if you talked forever, is just one of many things you'll discover in a group. To say things no one else can listen to, and be understood is very special.

A support group is the perfect place to make use of what you can do, or find out what you can do, or do nothing at all. We have found in group, that you have not thought anything we have not thought. You've not felt anything we've not felt. No emotion of yours is unknown to us. Each of us is unique, with surprising capabilities. We won't tell you how to think, feel, behave or what to say

or do. You'll be more than just welcome, we want you and need you. In no other place do you have a value quite like the one we give to each other. Join a group and let us show you how normal you are. And how special you are to us.

Danny Wooden

6/15/92

Thanks for the letter Danny. I'm sorry I didn't get it in before now. Support groups are a great place to find out more about others and yourself. To join an existing support group near you or to start one in your community, call your Case Manager.

Dr. McCluer Available for Speaking Engagements

Dear Editor:

On December 16, 1992, Dr. McCluer addressed approximately 30 nurses who work for the Hope Home Health Agency. Various topics relating to spinal cord injury were discussed, including pressure sore prevention, urinary management, bowel training, etc.

She was assisted by two quadriplegics, Randy Biddle and Kevin Sharih, who are clients of the Spinal Cord Commission. Having someone with a spinal cord injury to discuss their injury and demonstrate their findings made it a more interesting program for the audience.

If any other groups are interested in having a presentation on some aspect of spinal cord injury, please contact the Case Manager in your area or the central office, 324-9624. Dr. McCluer will be more than happy to schedule a session with your group.

Patti Rogers, ASCC

Fishing and Picnicing at Shores Lake

A Fishing Derby and Picnic was attended by thirtyfive clients, family members, Case Manager Kay Lynn and representatives from North Arkansas Surgical Supply and Fort Smith Rehabilitation Hospital on October 3, 1992, at Shores Lake. Shores Lake is a national forest recreational area located in Crawford County which has five wheelchair accessible fishing docks and an accessible covered pavilion. Prior to the outing the

Arkansas Game and Fish Commission stocked the lake.

A park ranger from the Forestry Service gave a history of Shores Lake and the Shores family and a nature lecture featuring colored posters of the area's flora and fauna, then distributed free snake posters. Mr. Bryant, father of Rodney Bryant the owner of North Arkansas Surgical Supply, cooked ham-



burgers, hot dog and his famous Barbecued Bologna Loaf - it's a secret recipe - 89 herbs and spices! (The bologna is highly recommended by Case Manager Kay Lynn). Connie Wiederspan, the Assistant Spinal Cord Injury Program Director of Fort Smith Rehab, provided the fishing contest prizes. As it turned out, everyone who caught ANYTHING got a prize.

Shores Lake also has a wheelchair accessible beach and swimming area with a ramp extending into the water. Last year, Case Manager Kay Lynn came up with an innovative way of assisting wheelchair users into the water: with the approval of Patti Rogers, Client Services Director of ASCC, Kay provided an antiquated emergency loaner wheelchair to the Shores Lake Park Rangers. This proved ideal for getting wheelchair users down the

ramp and into the water.

The outing was highly successful. ASCC secretary Gwen Brotherton took the photographs. What a good opportunity for fellowship and for clients to view Shores Lake and spread the word that finally there is a large and lovely facility that is wheelchair accessible in the Region VIII area.

The Technology Equipment Revolving Loan Fund

For many Arkansas with disabilities assistive technology is a necessity, not a luxury. Through the use of assistive technology such as electric wheelchairs, computers, van lifts, adaptive listening devices, and low vision aids, individuals with disabilities can actively participate in employment, education, community activities, and family life. However, assistive technology can be expensive. The high costs can make it difficult if not impossible for many Arkansans to receive the technology they need. To help Arkansans get the technology they need, legislation has been developed that will establish a Technology Equipment Revolving Loan Fund. The legislation will:

- Enable individuals with disabilities and older adults to purchase assistive technology, equipment and related services that will enhance their independence, productivity, and decrease their reliance on government support.
- Enable individuals with disabilities and older adults to pay for home modifications such as ramps, widened doorways and roll-in showers.
- Enable businesses to purchase assistive technology that will enable Arkansans with disabilities to gain and maintain employment.

- Enable Arkansans the opportunity to be integrated and make a valuable contribution to their community.
- Require that lower-interest, long-term loans be repaid so that the fund revolves, making loans available for individuals with disabilities and older adults for years to come.

This bill will be part of the 1993 legislative session. If you are interested in more information, contact ICAN (a program of the Division of Rehabilitation Services) at 1-800-828-2799 voice/tdd. Better yet, let your legislator know that you are interested.

Do Your Squeaky Wheels Get the Grease?

Your wheelchair is a vital link to your independence, but it needs your regular care and attention. Here are some helpful hints from The Institute for Rehabilitation and Research's (TIRR's) Department of Occupational Therapy in Houston, Texas on keeping your wheelchair in top condition:

Weekly

- Clean the frame of the wheelchair with a spray cleaner.
 Wipe car wax on the frame with a damp cloth, let it dry to a haze, and wipe it off with a dry cloth. Dirty metal parts don't work well together and wear out faster.
- Lint should be removed from around the axles with a bottle brush. Bearings must be replaced on the light weight chairs when worn out.
- Wheels should be checked for loose spokes and worn bearings. Spin the wheel to see if it wobbles. If so, it probably means that some adjustment is needed in the spokes.

Regular Maintenance

Pneumatic tires

- Check tread for excessive wear or patchy, uneven wear. Check tread and sidewalls for scrapes and cuts, and deterioration of the rubber. Check air valve for damage and be sure the valve-cap is not missing.
- Wipe soapy water over the tire to see where bubbles may rise. This will reveal air leaks.

Casters

• Check for signs of bending on sides and stem. Be sure the stem is firmly attached to fork. Evaluate threads and locking nut or retaining ring.

 Check stem bearing for excessive play both up and down, as well as forward and backward. Tighten as necessary.

Quick release axles (Lightweight wheelchair only)

- Wheels should be removed at least once a month to prevent the release button from freezing.
- Brakes
 - Check brakes and adjust them. Don't tighten them to the point where they peel rubber off the tire.
 - Check grade aids for proper operation.

Upholstery

 Check for equal tautness of each upholstery piece. Sling seat or back upholstery may contribute to the development of pressure sores. Tighten screws if loose and make adjustments in back.

General Wheelchair Care Instructions

- Record the serial number of your wheelchair and retain for your future reference. This number may be important when ordering replacement parts.
- Obtain the name, phone number and address of the medical supply vendor who provided you with the wheelchair. You should contact the vendor if any problems arise with your wheelchair.
- An annual maintenance review by the medical supply vendor is recommended.

Housing, from page 1

visually impaired persons are provided by better defined horizontal and vertical spaces through attention to color schemes of walls, counter tops, floor coverings, shelving and hardware.

In this innovative approach, project designers and participants have created a home which greatly enhances the day-to-day aspects of living for disabled occupants without the appearance of being so. Improvements are "low-tech" rather than relying on complex equipment. As a result, this home clearly demonstrates easily achievable "universal design" renovation techniques which can be applied to existing homes to affordably enhance the quality of life for any family.

According to Bill Freeman of PBHA, they will not modify and retrofit any more existing homes, but do plan to develop 12 other apartment units with some of the same features as this particular home. The apartments will be user-friendly, making them suitable for anyone.

Nathaniel's new home would not have been possible without the partnership and participation of the Little Rock office of the U.S. Department of Housing and Urban Development and John Suskie, State HUD Director. The following also provided invaluable assistance: The City of Pine Bluff, Maribeth Frazer, barrier-free consultant to HUD, A. W. Nelson, architect, Thorn's Construction, Doris Culver of ICAN, and many others.

To learn more about ways to make homes easier to live with through barrier-free design and the use of assistive devices and how to obtain financing for an accessible home, contact your local Housing Authority or the State HUD Office, County Farmer's Home Administration (FMHA) or your City Manager's Office.

From the Director

Happy New Year! It seems amazing to me that it can already

be 1993. The days, weeks and years seem to fly past. But actually many of us have looked forward to this month and year. January 1993 will be momentous for us. Nationally, the first Arkansan will be inaugurated President and we hope bring many positive changes to our Country. Here in Arkansas, our biannual legislative session begins, with our new Governor, Jim Guy Tucker, at the helm. The challenges that face our Arkansas legislators are not unlike those at the national level and we look again for positive change.

But change is hard. Many of us grow accustomed to things as they are, if not perfect at least familiar, and we balk at any change in our routines and our lives. 1993 will bring many changes, whether we want them or not. We are all well aware of the problems in health care and in our Medicaid and Medicare systems. These will change, as will the ways that agencies like our Spinal Cord Commission provide services. Dollars are scarce and we will be looking at many different ways to stretch them, to use them most optimally, developing new programs, expanding and reworking existing ones. I hope to use this column in the quarterly Courier to keep you aware of changes in the Spinal Cord Commission.

My challenge to you for 1993 is to be part of the change. Each of us has capability to make positive change in our lives. If you have not made your New Year's resolution yet, think about what you would like to see changed, in your life, your community, your state. Then resolve to do something to make it happen. The hardest part is to start! One way that you can impact change is to let your state representatives and senators know how you feel about legislation that affects you. If you hear on television or see in the paper a bill that affects you (like Medicaid changes, programs cuts or taxes) call or write your senator or representative and tell them: 1. how it will affect you, 2. what you want them to do (vote for or against). Your message can be short and sweet, handwritten or a brief phone call. They represent YOU, so let them know how you feel! Help make change!

Change is hard but change is good. It's going to happen, with or without you; so take part in making positive change in 1993. You will be amazed what you can accomplish. Cheryl L. Vines Executive Director

Rollin to the Music

Over the next several months many of us may see a number of individuals rolling along to the beat of their favorite tunes. Why the sudden increase in music lovers? The main reason is expected to be because of the benevolence of the Alabama Spinal Cord Injury Association (ASCIA) and the efforts of the Arkansas Spinal Cord Commission.

During the past year the Alabama SCIA obtained a grant to provide any individual with a spinal cord injury of less than one year a free

Sony AM/FM Cassette Walkman.

Because the Arkansas Spinal Cord Commission (ASCC) has the capability to best coordinate this service in Arkansas, the Alabama SCIA will work directly with each ASCC Case Manager. If you have been injured less than one year, are interested in receiving a free Sony Walkman and have not been contacted yet, call your ASCC Case Manager who will be happy to provide you with additional information so you too may begin "rockin and rollin"!



Skip Wilkins

Nationally acclaimed author, motivational speaker and gold medal winning wheelchair athlete Skip Wilkins is pictured here with ASCC Health Educator Ann Whitehead during his visit to Arkansas on October 19. He spoke to Arkansans with disabilities and rehabilitation patients and staff at Baptist Rehabilitation Center as a guest of United Medical Incorporated.

Skip Wilkins knows from personal experience about motivation and determination. Three days after his high school graduation in 1967 a water-skiing accident rendered him quadriplegic. Paralyzed from the shoulders down and a permanent wheelchair user, the high school football player with a college scholarship and dreams of a professional football career had to make changes in his plans and dreams.

With the help of family, friends and his wife of over 20 years, Wilkins has triumphed personally, professionally and athletically in helping others achieve victories in their lives. His book, The Real Race, describes his long road to triumph. "Doing your best is a lifetime job," said Wilkins. "Each of us has talents and abilities: it is what we do with them that counts." The Real Race and a video tape of Wilkins' presentation are available for loan from the ASCC Resource Library.

Local Builder Makes State Capitol More Accessible

Visitors to the State Capitol in Little Rock may have noticed recent changes on the south side of the Capitol and campus. Rankin Construction Corporation won the bid and installed an electric wheelchair lift beside the exterior steps leading from the ground to the floor level of the Rotunda. This will allow entrance to the State Capitol by wheelchair users approaching from the south, which faces Seventh Street. The project was completed in October.

Tucked in beside the exterior concrete steps on the south side of the Capitol is the newly constructed wheelchair lift. The lift measures 60" x 42" which will accommodate a wheelchair user and one other person. It has lift capacity of 750 lbs. Currently, for safety reasons, the user must summon Security to unlock the lift.

"This project brought a lot of personal satisfaction to me," was Rankin's comment while discussing the project. The total project, in addition to building the lift, involved making three more handicapped parking areas, two curb cuts and widening some sidewalks. In order to do that he had to move some flower beds and a sprinkler system.

Rankin has continued running his construction company from a power wheelchair after a motor vehicle crash in 1981 resulted in quadriplegia from spinal injury.

MINI VIDEO REVIEW

Attitudes, Choices and Skills is a 28 minute video designed to motivate the new wheelchair user to begin the difficult process of learning new skills. It features wheelchair users whose experiences and interests make them effective role models. It offers encouragement and supports a positive self image. This video is available for loan through the ASCC Resource and Education Center. Contact Loretta Decker at 324-9628.

Urine Odor

One of the unpleasant things that is sometimes associated with spinal cord injuries is a persistent urine odor. However, with careful attention to detail, this problem can usually be prevented. This article offers some practical suggestions.

- 1. The person who has the offensive odor may not be aware of it. After smelling any unpleasant odor continuously for several days one adapts and can no longer smell it. Anyone who lives in a town with a paper mill or refinery is aware of this adaptation. However if you go away for a few days, then return, the full effect is again noticed. Similarly the person who has a urine odor may no longer be aware of it and it would be a kindness to tactfully tell them. If you have a spinal cord injury and are concerned about possible odor, it may be wise to discuss it with a close friend and ask them to tell you any time an odor is noticeable.
- 2. Very careful hygiene is necessary. Regardless of the method of urinary management, there is always the possibility of occasionally spilling small amounts of urine on one's clothing or wheelchair cushion. Even when fresh urine has very little odor, the longer it stays, the stronger the odor becomes. Spills should be washed out as soon as possible and every effort made to prevent drops of urine from getting on clothing in the first place (for example, by using a protective plastic pad when catheterizing or emptying a leg bag). Cushion covers should be washed as often as needed. When there is a possibility of urine leakage, foam cushions are not advisa-



ble unless a waterproof cover is used over them.

3. Cleaning of equipment. One of the most common errors is in the technique of cleaning equipment for individuals who have an indwelling catheter or use a condom drainage with a leg bag. These products are often made of rubber (Latex) which absorbs odors much easier than plastic does. The most conscientious people seem to feel the best way to get really clean is to use hot water. Unfortunately, this is the worst thing to do! Hot water sets the odor into the rubber even worse, and the only solution is to discard the equipment and start over.

Catheters, leg bags and connecting tubing should always be

CLEANED WITH COLD WATER ONLY!

4. Alkaline urine. Normally fresh urine does not have a very strong or unpleasant odor because the urine is acid (pH 6-7). However if it becomes alkaline (pH 8-9), urine has a strong, very unpleasant odor that is obvious when emptying a leg bag or catheterizing. In addition to the odor, alkaline urine is undesirable because it is more favorable for bacteria to grow (causing infection) or for stones to form. One of the most common causes for alkaline urine is drinking carbonated beverages (any fizzy drink). Ideally these should be avoided completely, and certainly no more than one per day. Instead, drink water, Kool-aid, tea, cranberry or apple juice.

Ravenswood Equestrian Center

"It's really helped me a lot. I can tell the difference in my back, in my arms. Its's made me a lot stronger ... and it's fun!" said Donnie Sledge. A client of the Hot Springs Rehabilitation Center, and one of Ravenswood Equestrian Center's riders, Donnie has been working hard at rehabilitating from a spinal cord injury which he sustained a couple of months ago while doing some routing maintenance on his home.

The horseback therapy program is the result of a collaborative effort on the part of the Hot Springs Rehabilitation Center, and the Ravenswood Equestrian Center in Bismarck, AR. The program combines elements of classical hippo-therapy, which uses a horse as a therapy "tool" with the rider being passive, with equine-assisted therapy, in which the rider is active, and adds a dash of classical show riding.

Alan Phillips, Director of the therapy part of the program brings his considerable expertise as Director of Physical, Occupational and Recreational Therapy for Hot Springs Rehabilitation, as he designs the therapeutic programs. Judith Fletcher, owner and director of Ravenswood Equestrian Center, adds over 20 years' experience as a show horse and rider trainer to the program. What comes out of this synergy is exciting, rewarding and extremely effective.

Ravenswood is one of a small number of facilities that specifically trains horses for use by disabled people. The horses must know the difference between a spasm in a leg muscle and a command given by a leg. They must be able to set their cadence and stride to match the ability and the disability of each rider, and they

must know to freeze in place if someone looses his or her balance. The specific training for each individual client is different. But all the training in the world is worthless without the skill of the therapy side of the program.

The process generally begins with an evaluation to determine if an individual can benefit from the program. Physicians, PT, OT and RT get involved at this point, and their input goes to Alan, who decides on the actual program. Judy and her staff then figure out how to do it on a horse, and the rest takes place on the horse.

age girth, which is a girth equipped with a pair of leather wrapped steel handles, over a pair of fleece pads to make the ride more comfortable. This rig is commonly used to train circus and rodeo trick riders, but we've found another function for it. Judy Fletcher is serving as a backrider for Donnie. We often use backriders with our people, to provide an added measure of safety, as well as being able to help the person keep his hips in the middle of the horse, shoulders level and legs in good positions, etc. Getting on a 1200-1500 lb. animal can be intimidating enough for an able-



Left to right: ASCC Case Manager Bettie Tapp, Donnie Sledge, Judith Fletcher, and Ravenswood horse handler Robbie Jones.

The process tends to cut hospitalization time, speeds up the rehabilitation process, increases self-confidence and self image, normalizes muscle tone and can facilitate walking since the movement of a walking horse is very similar to that of a walking human. It's almost as though it makes the body remember how to walk in a way that can't be duplicated in a PT gym.

We use and design quite a bit of adaptive equipment as well. The photograph shows Donnie aboard an Appaloosa mare using a voltbodied person, but if your legs don't work and your back won't hold you up, it can be downright terrifying. A skilled backrider becomes the riders back and legs until their own back and legs or other muscle groups learn to do the job.

We've enjoyed some great successes, and look forward to more in the coming season. If you have questions about our program, or would like to volunteer, please don't hesitate to get in touch with us at Ravenswood Equestrian Center, Route 1, Box 473, Bismarck, AR 71929, phone (501) 865-3612.

SPINAL COURIER — 7

With Thanks

In 1992 the Spinal Cord Commission received many contributions from individuals and organizations. These gifts are important because the extra funds allow us to provide programs, services and make purchases that would not be possible in our regular budget.

These funds are maintained separately from regular State funds. Contributions to the Spinal Cord Commission are tax deductible and can be made in memory or honor of an individual or anonymously. Contributions may be in cash or in new or usable medical equipment.

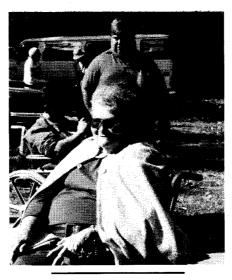
The following contributions were received in 1992:

Anonymous

Larry and Barbara Whittle

In Memory of Paul Rogers:
Mr. and Mrs. J.D. Hollensworth
Mr. and Mrs. Jimmie Hollensworth
Mr. and Mrs. Jerry Hollensworth
Mrs. Joe Baskin
Robert and Mary Lyons

Fall Festival and Fun Day



Mr. and Mrs. Travis Roberts Murphy's Jewelers Connie Kyle Janet Edwards Mr. and Mrs. Bob Jones Mr. and Mrs. Michael Epley Susan Morgan Robert Lyons

In Memory of Joe Mims: Caroline E. Mims

For additional information on making contributions to the Spinal Cord Commission, please contact Cheryl Vines at 324-9624.

A Fall Festival and Fun Day was held in October at beautiful De-Gray State Park. Activities included a cookout, barge ride, nature lecture on Bats, sing-a-long, and fishing in a stocked pond. Over 150 consumers, friends and family members attended.

The Arkansas Spinal Cord Commission worked with Arkansas State Parks and Tourism, Arkansas Game and Fish Commission, Walt Lumpkin representing National Medical Rentals and David Cossey representing American Home Patient for the success of another great outdoor recreational day. Kudos to Casemanagers Evelyn Wainright, Annie McKnight and Bettie Tapp for a successful Fall Festival and Fun Day.

Photo above - Ethel Coke, Linda Jones and friend socialize at DeGray State Park during the Fall Festival and Fun Day.

Printed on recycled paper.

SPINAL COURIER

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